

University of Groningen

Moving forward by moving back

Thombs, Brett D.; Coyne, James C.

Published in:
Journal of Psychosomatic Research

DOI:
[10.1016/j.jpsychores.2013.05.002](https://doi.org/10.1016/j.jpsychores.2013.05.002)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2013

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Thombs, B. D., & Coyne, J. C. (2013). Moving forward by moving back: Re-assessing guidelines for cancer distress screening. *Journal of Psychosomatic Research*, 75(1), 20-22.
<https://doi.org/10.1016/j.jpsychores.2013.05.002>

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.



Moving forward by moving back: Re-assessing guidelines for cancer distress screening

Brett D. Thombs ^{a,b,c,d,e,f,*}, James C. Coyne ^{g,h}

^a Lady Davis Institute for Medical Research, Jewish General Hospital, Montreal, Quebec, Canada

^b Department of Psychiatry, McGill University, Montreal, Quebec, Canada

^c Department of Epidemiology, Biostatistics, and Occupational Health, McGill University, Montreal, Quebec, Canada

^d Department of Medicine, McGill University, Montreal, Quebec, Canada

^e Department of Educational and Counselling Psychology, McGill University, Montreal, Quebec, Canada

^f Department of Psychology and School of Nursing, McGill University, Montreal, Quebec, Canada

^g Behavioral Oncology Program, Abramson Cancer Center and Department of Psychiatry, Perelman School of Medicine of the University of Pennsylvania, Philadelphia, PA, USA

^h Health Psychology Section, Department of Health Sciences, University Medical Center Groningen, University of Groningen, The Netherlands

ARTICLE INFO

Article history:

Received 22 April 2013

Received in revised form 7 May 2013

Accepted 8 May 2013

The Institute of Medicine (IOM) defines clinical guidelines as “statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options” (p. 4) [1]. However, many clinical guidelines are not based on evidence [1]. Instead, preference-based value judgments sometimes outweigh evidence in guideline-making [2], with the risk of this highest when guideline panels are comprised almost entirely of clinical specialty group members. Such panels make more non-evidence-based recommendations than multi-disciplinary panels [3], including recommendations for care provided by members of the specialty group [2].

There is consensus on the need for guideline reform [1], so that care addresses patient needs, but avoids interventions that consume scarce health care resources without proven patient benefit [4]. As part of the Choosing Wisely campaign, for instance, 26 US medical societies have each listed five commonly used tests or procedures that should be questioned by physicians and patients [5]. No organizations focused on mental health have done this.

Drs. Bultz and Carlson [6] faulted our systematic review of screening for psychological distress in cancer [7] because “it contravenes recommendations to screen broadly, which are based on prevalence studies demonstrating that patients experience distress in all of the physical, psychosocial and practical domains, with a real interplay among domains” (p. 1–17). They referred to distress screening guidelines published by the National Comprehensive Cancer Care Network (NCCN) [8]. They did not provide evidence from random-

ized controlled trials (RCTs) that patients screened using the NCCN paradigm have better health outcomes than patients not screened, even though this is a well-established standard for recommending screening [9,10].

The NCCN guidelines on distress screening were not based on evidence of patient benefit. There was no consideration of potential harms or whether resources would be more wisely used for other activities, such as improving care for the many patients with cancer who indicate they need psychosocial support, regardless of screening [11]. Instead, a panel comprised almost exclusively of mental health professionals drafted the guidelines without reference to any RCTs demonstrating that patients would benefit [8]. The NCCN should withdraw these guidelines and should document that a number of major issues are addressed prior to reconsidering any recommendation for distress screening.

First, what is meant by “screening” must be adequately defined. Across medical fields, the term “screening” indicates a process by which a screening tool is administered to individuals who are not known to be at risk of having a target medical condition. Based on a pre-defined criterion, patients potentially at risk are identified for further assessment and, if appropriate, treatment [9,10]. Screening for depression, for instance, involves the use of depression symptom questionnaires to identify patients who may have depression, but who have not sought treatment and whose depression has not already been recognized by healthcare providers [12]. In contrast, the term “screening” is commonly used in psycho-oncology to describe other kinds of interventions, which, while possibly useful, are not screening interventions based on any standard definition. Reflecting this, Bultz and Carlson suggested that our systematic review should have included evidence from 6 trials in which cancer care providers used psychosocially oriented questionnaires to inform care consultations regularly provided to all patients. Patient responses on questionnaires did not determine whether they would be offered the psychosocial services, however. That is, they were not used for screening.

Second, the concept of distress is poorly operationalized. It is not clear what a screen for “distress” is intended to detect. The most commonly used “distress screening tool” is the distress thermometer described in the NCCN guidelines [8]. This, and other ultra-short

* Corresponding author at: Jewish General Hospital; 4333 Cote Ste Catherine Road, Montreal, Quebec H3T 1E4, Canada. Tel.: +1 514 340 8222x5112.

E-mail address: brett.thombs@mcgill.ca (B.D. Thombs).

“distress screening tools” [13,14], have in some cases been evaluated to determine their accuracy to detect depressive disorders, i.e., as depression screening tools [13,14]. In other cases, these same measures have been tested for their ability to detect “cancer-related distress, defined by semi-structured interview” (p. 487) [15], referring to “an adjustment disorder with or without additional comorbid depression/anxiety” (p. 4671) [13]. In still other cases [13,14], cutoff scores on these tools have been based on identifying patients with a score above a cutoff on a longer psychological symptom measure, such as the Hospital Anxiety and Depression Scale (HADS). The logic of screening with one self-report measure to identify patients with a high score on a longer self-report measure and labeling the longer measure a “gold standard criterion for distress” is dubious. Cutoff scores on longer questionnaires, such as the HADS, are typically calibrated to maximize combined sensitivity and specificity for a disorder, such as depression. For the HADS, 40–50% of patients with positive screens may have depression [16], although this falls to 10–20% when patients already receiving services are appropriately excluded from consideration [16,17]. So, a positive screen on a “distress screener,” as calibrated against the HADS or another questionnaire, means that a patient has some probability (the positive predictive value of the distress screener to predict a positive screen on the longer questionnaire) of having another probability (the positive predictive value of the other questionnaire for depression). The meaning of this is not clear, and simply calling this “distress” does not alleviate the problem. Stretching the concept even further, Bultz and Carlson suggest that for the purpose of screening, distress should be operationalized multidimensionally, which in their research involves the simultaneous administration of different “screening tools” for general distress, anxiety, depression, suicidal ideation, pain, fatigue, nutrition and weight, as well as concerns about accommodations, transportation, parking, drug coverage, work and school, finances, and groceries [18].

This broad definition of distress relates to the third issue that must be addressed, which is the need for a clear understanding of what are appropriate targets for screening and how screening programs should be evaluated. Screening is a preventive intervention, and the United States Preventive Services Task Force [19], which evaluates evidence on preventive service interventions in primary care, provides a model to understand how screening with multiple targets needs to be evaluated. Primary care physicians are encouraged to screen for many different conditions, and many of them have psychosocial components (e.g., depression, intimate partner violence, alcohol abuse, smoking). Importantly, evidence for each of these screening interventions is evaluated separately. Otherwise, it would be impossible to determine which screening programs are beneficial and cost-effective. The same logic applies to psychosocial care in cancer settings. It may be the case that patients would benefit from being screened for many different problems. However, consistent with general principles of testing screening programs and expectations that scarce health care resources must be used wisely to be used effectively [4,5], a scattershot approach to screening, without evidence of what works and what doesn't work, does not serve the best interests of patients. Appropriate targets for screening are medical problems for which screening can lead to effective intervention. Problems with parking or insurance can be identified by simply asking patients, but do not constitute screening.

Once appropriate targets for screening are identified, the parameters for testing the screening program must be carefully considered. Bultz and Carlson argue that intervention efficacy has nothing to do with screening. This idea departs dramatically from current understandings of screening [9,10]. For a screening program to be successful, patients must agree to be screened, the screening test must identify a significant number of patients who are not already receiving services, patients must be engaged in an intervention, and they must obtain sufficiently positive treatment results to justify resource utilization [9,10,12]. Effective treatment is a necessary component of a successful screening program, but a trial of screening must be able to distinguish the effect of

screening versus the effect of providing additional intervention services that are not otherwise available to patients. Thus, an evaluation of distress screening should (1) determine trial eligibility and randomize patients prior to screening; (2) exclude patients already recognized as needing psychosocial care or already receiving psychosocial services; and (3) provide similar care management options to patients identified in the screening arm of the trial and patients in the trial arm not receiving screening, but who are identified as needing services via other mechanisms, such as their own request or routine clinical interaction.

The NCCN guidelines on distress screening [8] and other recommendations, such as the American College of Surgeons Commission on Cancer Distress Screening Standard [20] are not based on evidence from well-conducted RCTs that screening results in benefits to patients and would be a wise use of resources. As researchers and clinicians, we owe it to cancer patients to base clinical care decisions on rigorous evidence. Without evidence that distress screening improves health outcomes, there is a real concern that it would consume scarce resources, diverting them from patients already known to be in need. Sometimes moving forward requires taking a step back first. Advocates for psychosocial cancer care should choose wisely by reconsidering non-evidence-based recommendations on distress screening. Furthermore, they should insist that high-quality evidence from trials addressing well-defined questions be obtained prior to making recommendations.

Sources of funding

Dr. Thombs was supported by a New Investigator Award from the Canadian Institutes of Health Research.

Conflict of interest

All authors have completed the Unified Competing Interest form at http://www.icmje.org/coi_disclosure.pdf and declare that no authors have any conflict of interest disclosures for the past 3-year reporting period.

References

- [1] Institute of Medicine. Clinical practice guidelines we can trust. Washington, DC: National Academies Press; 2011.
- [2] Shaneyfelt T. In guidelines we cannot trust. *Arch Intern Med* 2012;172:1633–4.
- [3] Fretheim A, Schunemann HJ, Oxman AD. Improving the use of research evidence in guideline development: 5. Group processes. *Health Res Policy Syst* 2006;4:17.
- [4] Tilburt JC, Cassel CK. Why the ethics of parsimonious medicine is not the ethics of rationing. *JAMA* 2013;309:773–4.
- [5] Choosing wisely: an initiative of the ABIM Foundation. <http://www.choosingwisely.org/>. [Accessed April 18, 2013].
- [6] Bultz BD, Carlson LE. A commentary on 'Effects of screening for psychological distress on patient outcomes in cancer: A systematic review' *J Psychosom Res* 2013;75:18–9 [this issue].
- [7] Meijer A, Roseman M, Delisle VC, Milette K, Levis B, Syamchandra A, Stefanek ME, Stewart DE, de Jonge P, Coyne JC, Thombs BD. Effects of screening for psychological distress on patient outcomes in cancer: A systematic review. *J Psychosom Res* 2013;75:1–17 [this issue].
- [8] Holland JC, Andersen B, Breitbart WS, Buchmann LO, Compas B, Deshields TL, et al. Distress management. *J Natl Compr Canc Netw* 2013;11:190–209.
- [9] Wilson JM, Jungner G. Principles and practices of screening for disease. Geneva: World Health Organization; 1968.
- [10] Raffle A, Gray M. Screening: evidence and practice. UK: Oxford University Press; 2007.
- [11] Söller W, Maislinger S, König A, Devries A, Lukas P. Providing psychosocial support for breast cancer patients based on screening for distress within a consultation-liaison service. *Psychooncology* 2004;13:893–7.
- [12] Thombs BD, Coyne JC, Cuijpers P, de Jonge P, Gilbody S, Ioannidis JP, et al. Rethinking recommendations for screening for depression in primary care. *CMAJ* 2012;184:413–8.
- [13] Mitchell AJ. Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. *J Clin Oncol* 2007;25:4670–81.
- [14] Vodermaier A, Linden W, Siu C. Screening for emotional distress in cancer patients: a systematic review of assessment instruments. *J Natl Cancer Inst* 2009;101:1464–88.
- [15] Mitchell AJ. Short screening tools for cancer-related distress: a review and diagnostic validity meta-analysis. *J Natl Compr Canc Netw* 2010;8:487–94.

- [16] Meijer A, Roseman M, Milette K, Coyne JC, Stefanek ME, Ziegelstein RC, et al. Depression screening and patient outcomes in cancer: a systematic review. *PLoS One* 2011;6:e27181.
- [17] Palmer SC, Taggi A, Demichele A, Coyne JC. Is screening effective in detecting untreated psychiatric disorders among newly diagnosed breast cancer patients? *Cancer* 2012;118:2735–43.
- [18] Carlson LE, Groff SL, Maciejewski O, Bultz BD. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol* 2010;28:4884–91.
- [19] U.S. Preventive Services Task Force. U.S. Preventive Services Task Force. <http://www.uspreventiveservicestaskforce.org/>. [Accessed April 18, 2013].
- [20] Wagner LI, Spiegel D, Pearman T. Using the science of psychosocial care to implement the new American College of Surgeons Commission on Cancer Distress screening standard. *J Natl Compr Canc Netw* 2013;11:214–21.